

UNITED STATES DISTRICT COURT  
FOR THE  
DISTRICT OF MAINE

LORI ROY, )  
Petitioner, )  
vs., ) Docket No.:  
MARY C. MAYHEW, )  
Commissioner, DEPARTMENT )  
OF HEATH AND )  
HUMAN SERVICES and the DEPARTMENT )  
OF HEALTH AND HUMAN SERVICES )

**COMPLAINT  
(INJUNCTIVE RELIEF SOUGHT)**

1. Lori Roy is a 49 year old woman with a number of diagnoses. She has been diagnosed with quadriplegia, arthritis, osteoporosis, muscular dystrophy, a hiatal hernia, GERD, Werdnig Hoffman Syndrome, dysphagia, kyphoscoliosis and bronchial atelectasis. Ms. Roy is eligible for nursing home level of services and has been since 1996. Even though Ms. Roy has been eligible for nursing home level of services, she has been receiving services at home under a nursing home waiver. Due to a MaineCare rule-change, Ms. Roy is now at risk of being placed in an institution in violation of the Americans with Disabilities Act, 42 U.S.C. §12133 and Section 504 of the Rehabilitation Act (Rehab Act) of 1973, 29 U.S.C. §794. Ms. Roy therefore brings this action against the Commissioner of the Department of Health and Human Services (DHHS) requesting that MaineCare modify its policies so she can continue to receive services in her home.

**JURISDICTION AND VENUE**

2. The action is brought pursuant to Title II of the ADA, 42 U.S.C. § 12133, and Section 504 of the Rehabilitation Act of 1973, 29 U.S.C.A. § 794. The Department of Health and Human Services (DHHS) is a public entity subject to Title II of the ADA and a recipient of federal financial assistance under Section 504 of the Rehabilitation Act.

3. The Court has jurisdiction over the action for declaratory relief pursuant to 28 U.S.C. § 2201 and Rule 57 of the Federal Rules of Civil Procedure. Injunctive relief is authorized by 28 U.S.C. § 2202, and Rule 65 of the Federal Rules of Civil Procedure.

4. Venue is proper in the District of Maine pursuant to 28 U.S.C. § 1331(b)(2), as a substantial part of the events or omissions giving rise to these claims occurred within the State of Maine.

## PARTIES

5. Lori Roy is a 49-year-old MaineCare recipient. She lives at her home in the Town of Vassalboro, County of Kennebec, State of Maine.

6. Ms. Roy has a diagnosis of quadriplegia, arthritis, osteoporosis, muscular dystrophy, a hiatal hernia, GERD, Werdnig Hoffmann Syndrome, dysphagia, kyphoscoliosis and bronchial atelectasis. Ms. Roy is a qualified individual with a disability.

7. In 1996, Ms. Roy began receiving personal care services under then Section 22 of the MaineCare program, known then as the Home and Community Based Benefits for the Physical Disabled. Under Section 22, Ms. Roy directed her services. In 2014, DHHS incorporated Section 22 into Section 19, the Home and Community Benefits for Elderly and for Adults with Disabilities or, the Adults with Disabilities Waiver (ADW). Ms. Roy continues to receive services under Sec. 19. Ms. Roy directs her services under the Sec. 19 waiver.

8. Defendant Mary C. Mayhew is Commissioner of the Department of Health and Human Services (DHHS) for the State of Maine. Her principal place of business is in the City of Augusta, County of Kennebec, in the State of Maine. She has overall responsibility for administering Maine's Medicaid Program, called MaineCare. She is responsible for ensuring that the rules, policies and practices of the Maine Department of Health and Human Services are

conducted in compliance with the federal law, including the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and the Medicaid Act. She is sued in her official capacity only.

9. The Maine Department of Health and Human Services is Maine's single State agency responsible for the administration and supervision of Maine's Medicaid Program under Title XIX of the Social Security Act. The Maine Department of Health and Human Services receives federal financial assistance.

## **STATUTORY AND REGULATORY FRAME WORK**

### *The Americans with Disabilities Act and Its Integration Mandate*

10. On July 12, 1990, Congress enacted the ADA, 42 U.S.C. §§ 12101-12213 (ADA), establishing the most comprehensive civil rights laws for people with disabilities in our nation's history.

11. Congress stated in its findings that "historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem." 42 U.S.C. § 12101(a)(2).

12. Congress found that "discrimination against individuals with disabilities persists in ... institutionalization ... and access to public services." 42 U.S.C. § 12101(a)(3). It also found that "individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion . . . , failure to make modifications to existing facilities and practices. . . ., segregation, and relegation to lesser services, programs, activities, benefits, jobs, or other opportunities." 42 U.S.C. § 12101(a)(5).

13. A major purpose of the ADA is to "provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities," and to "provide

clear, strong, consistent and enforceable standards addressing discrimination against individuals with disabilities.” 42 U.S.C. § 12101(b)(1)&(2).

14. Title II of the ADA provides that “no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by such entity.” 42 U.S.C. § 12132.

15. “Discrimination” under the ADA includes the segregation of persons with disabilities from society as a result of unnecessary institutionalization. As the Senate Labor and Human Relations Committee observed: “One of the most debilitating forms of discrimination is segregation imposed by others ... Discrimination also includes exclusion, or denial of benefits, services, or other opportunities that are as effective and meaningful as those provided to others.” S. Rep. No. 116, 101st Cong., 1st Sess. 6 (1989). Thus, Congress recognized that “discrimination” against persons with disabilities entails more than just disparate treatment, and that simply requiring evenhanded treatment would not remedy all discrimination.

16. The regulations implementing the ADA require that: “a public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” 28 C.F.R. § 35.130(d). The affirmative duty embodied in 28 C.F.R. § 35.130(d) stems from the recognition that the failure to integrate individuals with disabilities in society (for example, through unnecessary institutionalization) constitutes unlawful discrimination under the ADA.

17. The United States Supreme Court in *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999), held that the unnecessary institutionalization of individuals with disabilities is a form of discrimination under Title II of the ADA. In doing so, the High Court interpreted the ADA’s “integration mandate” as requiring persons with disabilities to be served in the community

when: (1) the state treatment professionals determine that community-based treatment is appropriate; (2) the individual does not oppose community placement; and, (3) community placement can be reasonably accommodated. 527 U.S. at 607.

18. As has been shown by her current in-home placement, a community-based placement is desirable and appropriate for Ms. Roy and she has benefited from access to community-based services. Furthermore, her ongoing placement in the community can be reasonably accommodated.

19. Individuals at risk of institutionalization are protected by the *Olmstead* decision. *Steimel v. Wernert*, 823 F.3d 902 (7<sup>th</sup> Cir. 2016); *Davis v. Shah*, 821 F.3d 231 (2<sup>nd</sup> Cir. 2015); *M.R. v. Dreyfus*, 663 F.3d 1100 (9<sup>th</sup> Cir. 2011), amended by 697 F.3d 706 (9<sup>th</sup> Cir. 2012); *Fisher v. Okla. HeathCare Authority*, 335 F.3d 1175 (10th Cir. 2003).

20. Defendant's actions, taken under the color of state law, will deprive the Plaintiff of her federally protected rights.

*Section 504 of The Rehabilitation Act*

21. Section 504 of the Rehabilitation Act of 1973 provides, “[n]o otherwise qualified individual with a disability in the United States …, shall, solely by reason of his or her disability, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.” 29 U.S.C. § 794.

22. Regulations implementing Section 504 require a recipient of federal financial assistance to administer its services, programs, and activities in “the most integrated setting appropriate” to the needs of qualified individuals with disabilities. 28 C.F.R. § 41.51(d).

23. Regulations implementing Section 504 prohibit recipients of federal financial assistance from “[u]tiliz[ing] criteria or methods of administration … (i) [t]hat have the effect of subjecting qualified handicapped persons to discrimination on the basis of handicap [or] (ii) [t]hat

have the ... effect of substantially impairing accomplishment of the recipients' program with respect to handicapped persons." 45 C.F.R. § 84.4(b)(4); 28 C.F.R. § 41.51(b)(3)(i).

24. Because the relevant provisions of the Rehabilitation Act and its regulations are materially identical to the ADA, they are construed and applied in a manner consistent with the ADA. *Bruggeman, ex rel Bruggeman v. Blagojevich*, 324 F.3d 906 (7<sup>th</sup> Cir. 2003); *Radaszewski, ex rel. Radaszewski v. Maram*, 383 F.2d 599 (7<sup>th</sup> Cir. 2004); *Frederick L. v. Dep't of Public Welfare of Pennsylvania*, 364 F.3d 487 (3d Cir.2004)

*Medicaid and MaineCare Programs  
The State-Federal Medicaid Program*

25. Medicaid is a jointly funded state and federal program that provides medical services to low-income persons pursuant to Title XIX of the Social Security Act. 42 U.S.C. § 1396-1396v. The purpose of Medicaid is to furnish, as far as practicable, "medical assistance on behalf of...aged, blind or disabled individuals, whose income and resources are insufficient to meet the costs of necessary medical services" and "to help such families and individuals to attain or retain capability for independence or self-care...." 42 U.S.C. § 1396-1.

26. State participation in the Medicaid program is optional. States choosing to receive federal matching funds for their Medicaid program must comply with the requirements of the federal Medicaid Act and with the federal regulations governing state Medicaid programs promulgated by the U.S. Department of Health and Human Services (hereafter "HHS"). 42 U.S.C. § 1396, 42 C.F.R. §§ 430-484. The Centers for Medicare and Medicaid Services (CMS) is responsible for the administration of the Medicaid program.

27. The state Medicaid agency may place appropriate limits on services based on such criteria as medical necessity or on utilization control procedures.

28. Maine has chosen to participate in the Medicaid program. Maine calls its Medicaid program (MaineCare). MaineCare has prepared a state plan, which CMS has reviewed and

approved. That plan, along with relevant federal law and regulations, forms the foundation for the Maine's Medicaid program and establishes the State's obligations and responsibilities to Medicaid recipients. DHHS and its Commissioner, Mary Mayhew, administer the Medicaid program.

29. MaineCare provides Personal Support Services to medically eligible recipients through several different programs. One of these programs is the MaineCare Home and Community Benefits for the Elderly and for Adults with Disabilities Waiver Program. The State regulations governing the program are contained in Section 19 of the MaineCare Benefits Manual and the program is often referred to Section 19 or the Adults with Disabilities Waiver (ADW)

30. Section 19 defines Personal Support Services as:

those covered [Activities of Daily Living], [Instrumental Activities of Daily Living], and Health Maintenance Activities provided in a Member's residence by an individual employed by an agency qualified to work as a home Health aide, certified nursing assistant (CNA) or Personal Support Specialist, as appropriate, in accordance with an Authorized Plan of Care.

10-144 Chapter 101, Department of Health and Human Services, Chapt. II, Home and Community Based Benefits for the Elderly and for Adults with Disabilities, § 19.01-36.

## **FACTUAL ALLEGATIONS**

31. Lori Roy is a MaineCare recipient who has been determined eligible for 86 hours per week of personal support services (PSS), sometimes known as personal care assistance services, from her personal support specialist under the Section 19 Adults with Disabilities Waiver Program. Ms. Roy has received PSS services from since 1996.

32. Ms. Roy receives assistance with activities such as: bathing, dressing, errands, transportation for appointments, getting into and out of bed, eating, toilet use, meal preparation, housework, and care for skin conditions. The attendant also assists Ms. Roy with her needs when she is out in the community. He also assists with nebulizer treatment, "clapping" on her ribs to

loosen phlegm. The personal services that she receives through Section 19 waiver are vital to her safety, health, and well-being.

33. Of the 86 hours per week of attendant services Ms. Roy has been assessed as needing, Mr. Merrill provides them all. Mr. Merrill has been providing services to Ms. Roy since 1996, with some interruptions.

34. In December 2014, Defendant amended Sec. 19 of the MaineCare program to prohibit any personal support specialist (PSS) from receiving reimbursement for working more than 40 hours in a week with a single consumer. That regulation provides in pertinent part that effective January 1, 2015, services in excess of forty (40) hours per week provided by an individual worker to any individual member or household was a non-covered service. 10-144 Chapter 101, Department of Health and Human Services, MaineCare Benefits Manual (MBM), Chapt. II, Home and Community Based Benefits for the Elderly and for Adults with Disabilities, Sec. 19.05(L).

35. Also in December 2014, Defendant amended Sec. 19 by incorporating into Sec. 19., Sec. 22 of the MBM. Sec. 22 had been a consumer directed MaineCare waiver, which had substantially the same eligibility criteria as Sec. 19. Under Sec. 22, Ms. Roy received 86 hours of personal support services.

36. After Sec. 19 was amended, Ms. Roy attempted to comply with amended rule. Ms. Roy contacted Alpha One, the Fiscal Intermediary (FI) or Financial Management Services (FMS) provider of then Sec. 22 who provided her with names of potential attendants. None were available because they already had employment or because of where Ms. Roy lived.

37. Ms. Roy advertised on Craigslist and hired two new personal support specialists. Both personal support specialists were trained by Mr. Merrill. Both only worked for a short period of time before quitting. Mr. Merrill volunteered time to train both individuals.

38. Given her rural location and the demonstrated difficulty she has had hiring and retaining caregivers, Ms. Roy has been unable to find staff to consistently provide the 86 hours of services she needs, with the exception of Mr. Merrill.

39. Until January, 2016, Mr. Merrill worked, submitted time cards and was paid for 86 hours of service. On January 24, 2016, Mr. Merrill submitted a timesheet for hours worked between January, 10, 2016 and January 23, 2016. The timesheet showed 172 hours for that two week period; 86 hours per week. Mr. Merrill was told not to submit time cards for more than 40 hours of work or else he would not be paid anything. Mr. Merrill resubmitted his time care showing 80 hours of work for that two week period; 40 hours each week. He continues to work 86 hours a week and to submit time cards showing 40 hours of work each week.

40. July 8, 2016, Disability Rights Maine (DRM) submitted a request to the Department requested that the Defendant modify its rule capping the number of hours that Ms. Roy's PSS could be compensated for. DRM used a form previously supplied by DHHS. DRM resubmitted that request on July 28, 2016. There is no promulgated process for submitting requests to exceed the cap. DHHS has not developed a process advising Sec. 19 recipients or their providers about how to request exceptions to the 40 hour rule. There are no promulgated criteria by which requests to exceed the cap are evaluated or assessed. Sec. 19 recipients do not know how DHHS will decide to grant the exception or what criteria they will use in deciding to grant or deny such a request. There is no process by which Sec. 19 recipients can appeal an adverse determination. DHHS is administering a standardless program.

41 As a result of the rule change, Ms. Roy is at risk of not receiving the number or quality of support that she needs to remain in the community. For this reason, the rule change creates a serious risk of institutionalization for Ms. Roy.

42. Ms. Roy faces a severe risk of institutionalization if her primary caregiver is only paid for 40 hours per week; her primary caregiver will be unable to continue to work for her if he is only paid for 40 hours per week. Ms. Roy's rural location creates an extreme hardship with regard to hiring and retaining quality care.

**FIRST CLAIM FOR RELIEF**  
**(Title II of the Americans with Disabilities Act)**

43. Ms. Roy adopts and restates the allegations set forth in paragraphs 1-42 of the complaint.

44. Ms. Roy is a qualified person with disability; Ms. Roy has record of having a disability and Defendant has regarded Ms. Roy as a person with a disability. Ms. Roy's conditions substantially limit major life activities, including the major life activities of walking, working, and caring for herself.

44. Ms. Roy is a qualified person with disabilities in that she is capable of safely living at home with necessary services and she meets the essential eligibility requirements for the receipt of services from and participation in the State Medicaid program with reasonable modification to the rules, policies, and practices of that program, 42 U.S.C. §12131.

45. Defendants' cap on the number of hours a single caregiver can provide, which includes no exceptions process, deprives Ms. Roy of services that she requires to avoid segregation in an institution and remain in the integrated home setting that is appropriate to meet her needs. This constitutes unlawful discrimination in violation of the Americans with Disabilities Act, 42 U.S.C. §12132.

46. Defendants have utilized criteria and methods of administration that subjects Ms. Roy to discrimination on the basis of disability, including the imminent risk of unnecessary institutionalization, by failing to ensure that Ms. Roy has access to MaineCare covered services that

will meet her needs in the community in violation of the Americans with Disabilities Act, 42 U.S.C. § 12132..

47. Defendants have failed to make reasonable modifications in policies, practices or procedures, when modifications are necessary to afford the goods, services, facilities, privileges, advantages or accommodations to Plaintiff. Defendant has engaged in discrimination against Ms. Roy in violation of the Americans with Disabilities Act, 42 U.S.C. § 12133.

**SECOND CLAIM FOR RELIEF  
(Section 504 of the Rehabilitation Act)**

48. Plaintiff adopts and restates the allegations set forth in paragraphs 1-48 of her complaint.

49. Plaintiff is a “qualified person with disabilities” within the meaning of Section 504, because she has physical impairments that substantially limit one or more major life activities, and she meets the essential eligibility requirements for long term care under MaineCare. She also meets the eligibility requirements of Sec. 19.

50. As a recipient of federal financial assistance, the Maine DHHS is subject to Section 504 of the Rehabilitation Act, 29 U.S.C. §794(a), and its implementing regulation, 28 C.F.R. §41.51(d).

51. Defendants’ cap on the number of hours a single caregiver can provide, which includes no exceptions to the rule process deprives Plaintiff of services she requires to avoid segregation in an institution and remain in the integrated home setting that is appropriate to meet her needs. This constitutes unlawful discrimination in violation of Section 504 of the Rehabilitation Act, 29 U.S.C. §794, and its implementing regulation, 28 C.F.R. §41.51(d).

52. Defendants have utilized criteria and methods of administration that subjects

Plaintiff to discrimination on the basis of disability, including the imminent risk of unnecessary institutionalization, by failing to ensure that Plaintiff has access to MaineCare covered services that will meet her needs in the community in violation of Section 504 and its implementing regulations.

53. Defendants have failed to make reasonable modifications in policies, practices or procedures, when modifications are necessary to afford the goods, services, facilities, privileges, advantages or accommodations to Plaintiff. Defendant is in violation of 29 USC §794

54. Defendants' failure to accommodate Ms. Roy and modify its policies, procedures and practices establishes a cause of action pursuant to 29 U.S.C. §794a.

**THIRD CLAIM FOR RELIEF  
(Due Process Clause of the 14<sup>th</sup> Amendment)**

55. Ms. Roy adopts and restates all the allegations set forth in paragraphs 1 through 54 of her complaint.

56. The Due Process Clause of the Fourteenth Amendment provides that a state shall not "deprive any person of life, liberty, or property, without due process of law"

57. Ms. Roy has a protected property and liberty interest in continuing to receive personal support services in her home as a recipient of Sec. 19 services.

58. DHHS administers its program in such a way, that there is no process, protocol, rule or policy that allows for making application for exceptions to the 40 hour cap. DHHS has failed to provide Ms. Roy with notice of the opportunity to request an exception. DHHS has not developed standards, policies, procedures, policies or rules that allow it to evaluate or assess requests for exceptions to the 40 hour cap rule. DHHS failed to provide any process for appealing an adverse decision on a request for an exception to the 40 hour cap rule. As a result of the Department's actions, Ms. Roy was deprived of her property and liberty interests in violation of her rights under the Due Process Clause of the 14<sup>th</sup> Amendment.

59. This violation is an ongoing violation of federal law.

60. Defendants' violation of Plaintiff's rights under the 14<sup>th</sup> amendment to the U.S. Constitution establish a cause of action pursuant to 42 U.S.C. §1983 for declaratory, injunctive relief including attorneys' fees and costs.

### **RELIEF REQUESTED**

WSSHHEREFORE, plaintiff respectfully requests that the Court grant the following relief:

- A. Declare that the Defendants' failure to create a process for providing Ms. Roy with a reasonable modification of its policy creates a risk of unnecessary institutionalization and constituted unlawful discrimination in violation of Title II of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act.
- B. Require that the Defendants, its officers, agents, employees, attorneys, and all persons who are in active concert or participation with Defendants, to make a reasonable modification to MaineCare Benefits Manual section 19.05(L) so that Ms. Roy can continue to receive services in the community
- C. Require that the Defendants modify the MaineCare Benefits Manual to include a process for requesting and receiving a reasonable accommodation to Section 19.05(L).
- D. Require that the Defendants notify all persons receiving services under MaineCare Benefits Manual Section 19 and all persons and/or entities providing services under MaineCare Benefits Manual Section 19 regarding the availability of reasonable modifications.
- E. Grant preliminary and permanent injunctions requiring the Defendants, its officers, agents, employees, attorneys, and all persons who are in active concert or participation with her to provide for individualized coverage of Ms. Roy's service needs in the least restrictive, most integrated setting.

- F. Require that DHHS promulgate standards for reviewing and assessing requests for exceptions to MaineCare Benefits Manual Section 19.05(L), including a process for challenging adverse decisions and then publish those standards.
- G. Waive the requirement for the posting of a bond as security for the entry of preliminary relief.
- G. Award the Plaintiff the costs of the action and reasonable attorney's fees pursuant to 29 U.S.C. § 794a, 42 U.S.C. § 12133, 42 U.S.C. § 1988 and any other applicable provision of law.
- H. All such other and further relief as the Court deems to be just and equitable.

Dated: December 2, 2016

Respectfully submitted,

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